General

Guideline Title

End of life care for infants, children and young people with life-limiting conditions: planning and management.

Bibliographic Source(s)

National Guideline Alliance. End of life care for infants, children and young people with life-limiting conditions: planning and management. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Dec 7. 44 p. (NICE guideline; no. 61).

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Regulatory Alert

FDA Warning/Regulatory Alert

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- August 31, 2016 – Opioid pain and cough medicines combined with benzodiazepines : A U.S. Food and Drug Administration (FDA) review has found that the growing combined used of opioid medicines with benzodiazepines or other drugs that depress the central nervous system (CNS) has resulted in serious side effects, including slowed or difficult breathing and deaths. FDA is adding Boxed Warnings to the drug labeling of prescription opioid pain and prescription opioid cough medicines and benzodiazepines.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation) and is defined at the end of the "Major Recommendations" field.

In this guideline:

- 'Children and young people' refers to everyone under 18 years old. This includes neonates and infants.
- 'Parents or carers' refers to the people with parental responsibility for a child or young person. If the child or young person or their parents or carers (as appropriate) wish, other family members (for example, siblings or grandparents) or people important to them (for example, friends, boyfriends or girlfriends) should also be given information, and be involved in discussions about care.

See the original guideline document for definitions of other terms used in this guideline and for footnotes with information about prescribing medications.

General Principles

Recognise that children and young people with life-limiting conditions and their parents or carers have a central role in decision-making and care planning.

Discuss and regularly review with children and young people and their parents or carers how they want to be involved in making decisions about their care, because this varies between individuals, at different times, and depending on what decisions are being made.

Explain to children and young people and to their parents or carers that their contribution to decisions about their care is very important, but that they do not have to make decisions alone and the multidisciplinary team will be involved as well.

When difficult decisions must be made about end of life care, give children and young people and their parents or carers enough time and opportunities for discussions.

Be aware that continuity of care is important to children and young people and their parents or carers. If possible, avoid frequent changes to the healthcare professionals caring for them.

Be aware that siblings will need support to cope with:

- Their brother's or sister's condition and death
- The effects of their parents' or carers' grieving

This may include social, practical, psychological and spiritual support.

Be aware that other family members (for example, grandparents) and people important to the child or young person (for example, friends, boyfriends or girlfriends) may need support. This may include social, practical, emotional, psychological, and spiritual support.

When developing plans for the care of the child or the young person with a life-limiting condition, use parallel planning to take account of possible unpredictability in the course of the condition.

Communication

Think about how to provide information for children and young people with life-limiting conditions, taking into account their age and level of understanding. When appropriate, use formats such as:

- One-to-one discussion
- Play, art and music activities
- Written materials and pictures
- Digital media, for example, social media

When deciding how best to communicate with the individual child or young person and their parents or carers, focus on their views and take account of:

- Their personal and family situation
- Their religious, spiritual and cultural beliefs and values
- Any special needs, such as communication aids or the need for interpreters

Ask children and young people with life-limiting conditions and their parents or carers:

- If there are other people important to them (such as friends, boyfriends or girlfriends, teachers, or foster parents) who they would like to be involved, and if so

- How they would like those people to provide a supporting role

Think about how best to communicate with each child or young person and their parents or carers:

- When the life-limiting condition is first recognised
- When reviewing and developing the Advance Care Plan
- If their condition worsens
- When they are approaching the end of life

Ensure that all parents or carers are given the information and opportunities for discussion that they need.

When deciding which healthcare professional should lead on communication at a particular stage in a child or young person's illness, take account of:

- Their expertise and ability to discuss the topics that are important at that time
- Their availability, for example, if frequent discussions are needed during an acute illness or near the end of life
- The views of the child or young person and their parents or carers

Providing Information

Be aware that most children and young people with life-limiting conditions and their parents or carers want to be fully informed about the condition and its management, and they value information that is:

- Specific to the child's or young person's individual circumstances
- Clearly explained and understandable
- Consistent
- Up-to-date
- Provided verbally and in writing

Be aware that some children and young people and parents or carers may be anxious about receiving information about their condition.

Ask how children and young people and their parents or carers would like to discuss the life-limiting condition. For example:

- Ask which topics they feel are important and would particularly want information on.
- Ask whether there are topics they do not want detailed information on, and discuss their concerns.
- If appropriate, ask parents or carers whether they think their child understands their condition and its management, and which professional their child would like to talk to about it.
- If appropriate, ask parents or carers what they think their child should be told about their condition.
- Discuss with the child or young person and their parents or carers their right to confidentiality and how information about their condition will be shared.
- Review these issues with them regularly, because their feelings and circumstances may change over time, and they may need different information at different times.

When talking to children or young people and their parents or carers:

- Be sensitive, honest and realistic
- Give reassurance when appropriate
- Discuss any uncertainties about the condition and treatment

Be alert for signs or situations that the child or young person or their parents or carers need more information or discussions, for example, if:

- They are more anxious or concerned
- The child or young person's condition deteriorates
- A significant change to the treatment plan is needed

Provide children and young people and their parents and carers with the information they need on:

- Their role and participation in Advance Care Planning (see "Advance Care Planning" below)
- The membership of their multidisciplinary team and the responsibilities of each professional (see "Multidisciplinary Team" below)
- The care options available to them, including specific treatments and their preferred place of care and place of death (see "Preferred Place

of Care and Place of Death" below)
- Any relevant resources or support available to them

Care Planning and Support Throughout the Child or Young Person's Life

When a life-limiting condition is diagnosed, tell the child or young person (if appropriate) and their parents or carers about the condition and what it may mean for them (see recommendations under "General Principles" above on support for other family members and people who are important to the child or young person).

Every child or young person with a life-limiting condition should have a named medical specialist who leads on and coordinates their care. Explain to the child or young person and their parents or carers that their named medical specialist may change if the care that is needed or the care setting changes.

Manage transition from children's to adults' services in line with the NICE guideline on transition from children's to adults' services .

In all discussions with children and young people and their parents or carers explore with them whether, based on their beliefs and values, there are any aspects of care about which they have particular views or feelings.

Advance Care Planning

Develop and record an Advance Care Plan at an appropriate time for the current and future care of each child or young person with a life-limiting condition. The Advance Care Plan should include:

- Demographic information about the child or young person and their family
- Up-to-date contact information for:
    - The child or young person's parents or carers and
    - Key professionals involved in care
- A statement about who has responsibility for giving consent
- A summary of the life-limiting condition
- An agreed approach to communicating with and providing information to the child or young person and their parents or carers
- An outline of the child or young person's life ambitions and wishes, for example, on:
    - Family and other relationships
    - Social activities and participation
    - Education
    - How to incorporate their religious, spiritual, and cultural beliefs and values into their care
- A record of significant discussions with the child or young person and their parents or carers
- Agreed treatment plans and objectives
- Education plans, if relevant
- A record of any discussions and decisions that have taken place on:
    - Preferred place of care and place of death
    - Organ and tissue donation (see also "Organ and Tissue Donation" below)
    - Management of life-threatening events, including plans for resuscitation or life support
    - Specific wishes, for example, on funeral arrangements and care of the body
- A distribution list for the Advance Care Plan

Begin discussing an Advance Care Plan with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition. For each individual think about who should take part in the discussion, for example:

- Obstetricians
- Midwives
- Neonatologists
- Specialists in the life-limiting condition
- A member of the specialist paediatric palliative care team (see "Multidisciplinary Team" below)

Develop and regularly review Advance Care Plans:

- With relevant members of the multidisciplinary team and

- In discussion with the child or young person and their parents or carers

When developing the Advance Care Plan, take account of the beliefs and values of the child or young person and their parents or carers.

Explain to children and young people and their parents or carers that Advance Care Planning should:

- Help them be involved in planning their care and give them time to think about their views carefully
- Help them to understand the life-limiting condition and its management
- Help to prepare for possible future difficulties or complications
- Support continuity of care, for example, if there are changes in the professionals involved or in the care setting (such as a hospital admission or discharge)

Share the Advance Care Plan with the child or young person and their parents or carers (as appropriate), and think about which professionals and services involved in the individual child or young person's care should also see it, for example:

- General practitioners (GPs)
- Hospital consultants
- Hospices
- Respite centres
- Nursing services (community or specialist)
- School and other education services
- Ambulance service

Update the Advance Care Plan when needed, for example, if:

- New professionals become involved
- The care setting changes (for example, hospital admission or discharge)
- The child or young person and their parents or carers move home

Discuss the changes with the child or young person (if appropriate) and their parents or carers.

Share the Advance Care Plan with everyone involved each time it is updated.

When making an Advance Care Plan, discuss with the child or young person and their parents or carers:

- The nature of the life-limiting condition, its likely consequences and its prognosis
- The expected benefits and possible harms of the management options

Be aware that all children and young people with life-limiting conditions should have an Advance Care Plan in their medical record, and that this should not be confused with a do-not-attempt-resuscitation order.

Be aware that any existing resuscitation plan for a child or young person may need to be changed in some circumstances, for example, if they are undergoing general anaesthesia.

Organ and Tissue Donation

For information on organ donation (including donor identification and consent, and when and how to discuss the topic), see the NICE guideline on organ donation for transplantation.

Talk to the child or young person and their parents or carers about organ or tissue donation, and explore their views and feelings on this.

Explain to the child or young person and their parents or carers which organs or tissues (if any) it may be possible to donate.

Involve the organ donation service if needed. If organ or tissue donation is not possible, explain why.

If the child or young person is eligible to donate organs or tissue, ask them if they and their parents or carers (as appropriate) would like to discuss this, and if so:

- Provide written information if needed
- Discuss how deciding to donate could affect their care, for example, by changing their place of care and place of death
- Explain the practical policies and procedures involved

If the child or young person does not have the capacity to decide about organ and tissue donation, ask their parents or carers to make the decision.

Emotional and Psychological Support and Interventions

Be aware that children and young people with life-limiting conditions and their parents or carers may have:

- Emotional and psychological distress and crises
- Relationship difficulties
- Mental health problems

Be aware that children and young people and their parents or carers may need support, and sometimes expert psychological intervention, to help with distress, coping, and building resilience.

Be aware that children and young people may experience rapid changes in their condition and so might need emergency interventions and urgent access to psychological services.

Be aware of the specific emotional and psychological difficulties that may affect children and young people who have learning difficulties or problems with communication.

Provide information to children and young people and their parents or carers about the emotional and psychological support available and how to access it.

Regularly discuss emotional and psychological wellbeing with children and young people and their parents or carers, particularly at times of change such as:

- When the life-limiting condition is diagnosed
- If their clinical condition deteriorates
- If their personal circumstances change
- If there are changes to their nursery care, school or college arrangements, or their employment
- If there are changes to their clinical care, for example, if their care changes focus from treating the condition to end of life care

Social and Practical Support

Be aware that children and young people with life-limiting conditions and their parents or carers have varied social and practical support needs, and that those needs may change during the course of their condition. This may include:

- Material support, for example, housing or adaptations to their home, or equipment for home drug infusions
- Practical support, such as access to respite care
- Technical support, such as training and help with administering drug infusions at home
- Education support, for example, from hospital school services
- Financial support

Religious, Spiritual and Cultural Support

Ask children and young people with life-limiting conditions and their parents or carers if they want to discuss the beliefs and values (for example, religious, spiritual or cultural) that are important to them, and how these should influence their care. Be aware that they may need to discuss their beliefs and values more than once.

Take account of the beliefs and values of children and young people and of their parents and carers in all discussions with them and when making decisions about their care.

Be aware that:

- Some children and young people and their parents or carers find discussions about their beliefs and values difficult or upsetting
- Others find these discussions reassuring and helpful

Be aware that children and young people may feel differently to their parents, carers, or healthcare professionals about how their beliefs and values should influence their care. If there is disagreement, try to make a mutually acceptable care plan, and if necessary involve the chaplaincy service or another facilitator.

Care of the Child or Young Person Who Is Approaching the End of Life

Attempt resuscitation for children and young people with life-limiting conditions, unless there is a 'do not attempt resuscitation' order in place.

Be aware that discussing the Advance Care Plan can be distressing for children and young people who are approaching the end of life and their parents or carers, and they may:

- Be reluctant to think about end of life care
- Have difficulties discussing end of life care with the professionals or with one another
- Have differences of opinion about the care plan

When making or reviewing the Advance Care Plan for a child or young person approaching the end of life, talk to the parents or carers about the care and support they can expect when the child or young person dies. Discuss their personal needs and feelings about this.

When a child or young person is approaching the end of life, think about and discuss with them and their parents or carers their specific support needs. Review these needs regularly.

When thinking about the possibility of treatment withdrawal for a child or young person who is approaching the end of life, take into account their beliefs, values and wishes and those of their parents or carers.

Be aware of the importance of talking about dying, and if appropriate discuss with children and young people and their parents or carers:

- Whether they want and are able to talk about dying
- Whether they or their parents or carers would like support in talking to each other about this

Take account of the beliefs and values of children and young people and their parents or carers when thinking about funeral arrangements and the care of the child or young person's body after death.

When a child or young person is approaching the end of life, discuss with their parents or carers what would help them, for example:

- Important rituals
- Recording or preserving memories (for example, with photographs, hair locks or hand prints)
- Plans for social media content

Preferred Place of Care and Place of Death

Discuss with children and young people with life-limiting conditions and their parents or carers where they would prefer to be cared for and where they would prefer to die.

Agree the preferred place of care and place of death with children and young people and their parents or carers, taking into account:

- Their wishes, which are personal and individual
- Their religious, spiritual and cultural values
- The views of relevant and experienced healthcare professionals
- Safety and practicality

If possible, services should ensure that children and young people can be cared for at their preferred place of care and die at their preferred place of death.

Explain that the place of care or place of death may change, for example:

- If the child or young person and their parents or carers change their minds or
- For clinical reasons or
- Due to problems with service provision

When discussing possible places of care or places of death with children and young people and their parents or carers, provide information about:

- The various care settings (for example, home, hospice or hospital care)
- The care and support available in each setting
- Practical and safety issues

If the child or young person and their parents or carers prefer care at home, take into account and discuss the practical considerations with them,

such as the possible need for:

- Home adaptations
- Changes to living arrangements
- Equipment and support

If it is suspected that a child or young person may die soon and they are not in their preferred place of death, think about whether rapid transfer is possible and in their best interest. Discuss this with them and their parents or carers.

When planning rapid transfer to the preferred place of death, review and if necessary update the Advance Care Plan in discussion with the child or young person and their parents or carers and with the healthcare professionals who will be involved following the transfer. The updated Advance Care Plan should include a record of:

- Any intended changes to care and when they should happen
- Care plans that cover:
    - The final hours or days of life
    - What will happen if the child or young person lives longer than expected
    - Support for the family after the child or young person dies
    - Care of the child's or young person's body after death
- The professionals who will be involved and their responsibilities
- The professionals who will help with the practical and administrative arrangements after the death

When planning rapid transfer of a child or young person to their intended place of death:

- Be aware that the course of their condition may be unpredictable, and that they may die sooner or later than expected
- Discuss any uncertainties about the course of their condition and how this could affect their care with them and their parents or carers
- Ensure that relevant changes to the Advance Care Plan are implemented

Think about using a rapid transfer process (see the "Rapid Transfer Arrangements" section below) to allow the child or young person to be in their preferred place of death when withdrawing life-sustaining treatments, such as ventilation.

Before rapid transfer, agree with the parents or carers where the child's or young person's body will be cared for after their death.

Managing Distressing Symptoms

Involve the specialist paediatric palliative care team if a child or young person has unresolved distressing symptoms as they approach the end of life (see "Multidisciplinary Team" below for who should be in this team).

Managing Pain

When assessing and managing pain, be aware that various factors can contribute to it, including:

- Biological factors, for example, musculoskeletal disorders or constipation
- Environmental factors, such as an uncomfortable or noisy care setting
- Psychological factors, such as anxiety and depression
- Social, emotional, religious, spiritual or cultural considerations

When assessing pain in children and young people:

- Use an age-appropriate approach that takes account of their stage of development and ability to communicate
- Try to identify what is causing or contributing to their pain, and be aware that this may not relate to the life-limiting condition
- Take into account the following causes of pain and distress that might have been overlooked, particularly in children and young people who cannot communicate:
    - Neuropathic pain (for example, associated with cancer)
    - Gastrointestinal pain (for example, associated with diarrhoea or constipation)
    - Bladder pain (for example, caused by urinary retention)
    - Bone pain (for example, associated with metabolic diseases)
    - Pressure ulcers
    - Headache (for example, caused by raised intracranial pressure)

- Musculoskeletal pain (particularly if they have neurological disabilities)
- Dental pain

Be aware that pain, discomfort and distress may be caused by a combination of factors, which will need an individualised management approach.

For children and young people who have pain or have had it before, regularly reassess for its presence and severity even if they are not having treatment for it.

Think about non-pharmacological interventions for pain management, such as:

- Changes that may help them to relax, for example:
  - Environmental adjustments (for example, reducing noise)
  - Music
  - Physical contact such as touch, holding or massage
- Local hot or cold applications to the site of pain
- Comfort measures, such as sucrose for neonates

When tailoring pain treatment for an individual child or young person, take into account their views and those of their parents or carers on:

- The benefits of pain treatment
- The possible side effects of analgesia for moderate to severe pain (such as opioids), for example
  - Unwanted sedation
  - Reduced mobility
  - Constipation

Consider using a stepwise approach to analgesia in children and young people, based on pain severity and persistence:

- For mild pain, consider paracetamol[1] or ibuprofen[2] sequentially, and then in combination if needed
- For moderate to severe pain, consider one of the following options:
  - Paracetamol[1] or ibuprofen[2] sequentially, and then in combination if needed or
  - Low-dose oral opioids (such as morphine)[3,4] or
  - Transmucosal opioids or
  - Subcutaneous opioids or
  - Intravenously infused opioids (if a central venous catheter is in place)

If treatment with a specific opioid does not give adequate pain relief or if it causes unacceptable side effects, think about trying an alternative opioid preparation.

When using opioids, titrate treatment to find the minimal effective dose that will relieve and prevent pain.

Titrate treatment to provide continuous background analgesia, and prescribe additional doses for breakthrough pain if this occurs.

In addition to background analgesia, consider giving anticipatory doses of analgesia for children and young people who have pain at predictable times (for example, when changing dressings, or when moving and handling). Do not include anticipatory doses when calculating the required daily background dose of analgesia.

Calculate opioid dosages for children and young people who are approaching the end of life using weight rather than age, because they may be underweight for their age.

If you suspect neuropathic pain and standard analgesia is not helping, consider a trial with other medicines, such as:

- Gabapentin[5] or
- A low-dose tricyclic antidepressant (for example, amitriptyline[6]) or
- An anti-N-methyl-d-aspartate (NMDA) agent (for example, ketamine[7] or methadone[8]), used under guidance from a specialist.

Managing Agitation

Be aware that as children and young people with life-limiting conditions approach the end of life they may:

- Become agitated, shown by restlessness, irritability, aggressive behaviour, crying or other distress
- Show signs of delirium, such as confusion, disrupted attention, disordered speech and hallucinations

If a child or young person who is approaching the end of life becomes agitated or delirious, make sure that they are safe from physical injury.

If a child or young person becomes agitated as they are approaching the end of life, look for causes and factors that may be contributing to this, including:

- Medical disorders and conditions such as pain, hypoxia, anaemia, dehydration, urinary retention or constipation
- Psychological factors such as fear, anxiety or depression
- Adverse effects from medication

For children and young people with a neurological disability who are approaching the end of life, be aware that the signs and symptoms of agitation or delirium can be mistaken for the signs and symptoms of seizures or dystonia.

If a child or young person who is approaching the end of life needs treatment for agitation:

- Identify and if possible treat any medical or psychological conditions that may be contributing to it
- Think about non-pharmacological interventions, such as:
    - Calm speaking, reassurance, distraction, and physical contact such as holding and touch
    - Changes to the environment to make it more comfortable, calm and reassuring, to reduce noise and lighting, to maintain a comfortable room temperature, and to provide familiar objects and people and relaxing music
    - Religious and spiritual support if this is wanted and helpful
- Think about pharmacological interventions (beginning with low doses and increasing if necessary). Drugs to think about using include:
    - Benzodiazepines, such as midazolam,[9] diazepam[10] or lorazepam[11]
    - Neuroleptics, such as haloperidol[12] or levomepromazine[13]

Managing Seizures

If a child or young person is approaching the end of life and has a seizure, look for and if possible treat or remove any potential causes, triggers or contributing factors, for example:

- Fever
- Electrolyte disturbances
- Drug reactions
- Sleep deprivation
- Pain
- Excessive environmental stimulation

If a child or young person is thought to be at increased risk of seizures (for example, because they have had seizures before or because of an existing brain disorder), include seizure management in their Advance Care Plan. Think about the benefits and drawbacks of specific seizure treatments and:

- Take into account how any decisions could affect the choices available for place of care and place of death and
- Discuss this with the child or young person and their parents or carers

For children and young people who are approaching the end of life, be aware that abnormal movements (such as dystonic spasms) might be mistaken for seizures. If in doubt seek specialist advice.

If a child or young person is approaching the end of life and is thought to be at increased risk of seizures, explain to them and their parents or carers:

- How likely it is that they may have a seizure
- What they might notice if a seizure happens
- That seizures can be frightening or upsetting
- What parents or carers should do if a seizure happens at home (for example, placing the child or young person in a safe position)

Ensure that parents or carers who have been provided with anticonvulsive therapy (such as buccal midazolam) know how and when to use it if the child or young person has a seizure at home.

Managing Respiratory Distress

If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing, think about and if possible treat the likely contributing factors or causes. If these are likely to be caused by:

- Anxiety:
  - Discuss why they are anxious
  - Reassure them and manage the anxiety accordingly
  - Consider breathing techniques and guided imagery
  - Consider anxiolytic agents
- Physical discomfort – think about what could be causing the discomfort (for example, their position) and help them with it if possible.
- Environmental factors – think about environmental changes such as changing the temperature.
- Accumulated airway secretions – think about repositioning, airway suctioning, physiotherapy or anti-secretory drugs.
- Medical disorders (for example, pneumonia, heart failure, sepsis or acidosis) – use appropriate interventions such as:
  - Bronchodilators
  - Nebulised saline
  - Opioids
  - Oxygen supplementation

For children and young people who are approaching the end of life and have respiratory distress, breathlessness or noisy breathing that needs further assessment, consider referral to an appropriate specialist (for example, a respiratory or cardiac specialist).

If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing:

- Explain to them and to their parents or carers that these symptoms are common
- Discuss the likely causes or contributing factors
- Discuss any treatments that may help

Managing Hydration

If a child or young person with a life-limiting condition is approaching the end of life or is dying, discuss how to manage their fluid needs with them and their parents or carers.

If a child or young person is dying, encourage and support them to drink if they want to and are able.

If a child or young person is dying, continue to provide them with lip and mouth care.

If a child or young person is dying and cannot drink, discuss with them (as appropriate) and their parents or carers whether starting or continuing enteral tube or intravenous fluids is in their best interests.

Be aware that enteral tube and intravenous fluids may have a significant effect on care, may be a burden for children and young people, and may mean the place of care and place of death need to be changed.

If a child or young person is given enteral or intravenous fluids, review this decision regularly to make sure it continues to be in their best interests.

Managing Nutrition

If a child or young person is approaching the end of life or is dying, discuss how to manage their nutritional needs with them and their parents or carers.

If a child or young person with a life-limiting condition is dying, encourage and support them to eat if they want to and are able.

If a child or young person is dying and they are receiving enteral tube feeding or intravenous nutrition:

- Discuss with them (as appropriate) and their parents or carers whether continuing this is in their best interest and
- Review this decision regularly

Recognising That a Child or Young Person Is Likely to Die within Hours or Days

For children and young people with life-limiting conditions who are approaching the end of life:

- Be aware that there is often uncertainty around when they are likely to die
- Be aware that there are various symptoms and signs (individually or in combination) that indicate they are likely to die within hours or days
- Take into account the wider clinical context

When assessing whether a child or young person is likely to die within hours or days, be aware that the following signs are common in the last hours or days of life, and monitor these non-invasively as far as possible:

- A change of breathing pattern (for example, noisy, laboured or irregular breathing)
- Impaired peripheral perfusion (which can be indicated by a pale or grey appearance, or a prolonged capillary refill time), including temperature instability
- Loss of interest in or ability to tolerate drinks or food
- A marked and unexplained fall in urine output
- An altered level of awareness (for example, reduced consciousness, alertness or responsiveness, excessive sleeping, or confusion)
- Intractable seizures that keep occurring even with optimal management
- New onset of profound weakness
- Increasing pain and need for analgesia

When assessing symptoms and signs to decide whether a child or young person is likely to die within hours or days, take into account the wider clinical context, including:

- Their normal clinical baseline
- Past clinical events (such as previous episodes of temporary deterioration)
- The overall progression of their condition

When assessing whether a child or young person is likely to die within hours or days, take into account the clinical judgement of healthcare professionals experienced in end of life care.

If the child or young person or their parents or carers feel that they are likely to die within hours or days:

- Be aware that they may be correct
- Discuss their concerns with them

When a child or young person is likely to die within hours or days, support them and their parents or carers by:

- Listening to any fears or anxieties they have and
- Showing empathy and compassion

When a child or young person is likely to die within hours or days:

- Be aware that they or their parents or carers may not express their feelings openly, and may:
    - Have intense and varied feelings such as fear, hopelessness or anger or
    - Become more accepting of the inevitability of death
- Give them and their parents or carers opportunities to talk

If a child or young person is likely to die within hours or days, explain to them and their parents or carers:

- Why you think this is likely, and any uncertainties
- What clinical changes can be expected
- Whether you think the treatment plan should be changed

When children and young people become seriously ill and are likely to die within hours or days, provide care as specified in their Advance Care Plan and review if needed.

Be aware that children and young people may have difficulty asking directly if they are going to die or are dying. Explore and discuss their concerns if you think they want to talk about this.

Be aware that parents or carers may have difficulty asking directly if a child or young person is dying. Explore and discuss their concerns if you think they want to talk about this.

If a child or young person may be approaching the end of life and they or their parents or carers want to be involved in making decisions about

their care, discuss and review their Advance Care Plan with them.

When a child or young person is approaching the end of life, discuss with them and their parents or carers and with relevant healthcare professionals:

- Any available invasive treatments that might be in their best interest
- Any interventions they are currently receiving that may no longer be in their best interest

If withdrawing a treatment for a child or young person who is dying, explain to them and to their parents or carers that it is often difficult to tell if or how this may affect them, or when they will die.

When a child or young person is likely to die within hours or days, ensure that they can have private time with their parents or carers.

Care and Support for Parents, Carers and Healthcare Professionals in Relation to the Death of a Child or Young Person

Discuss with parents or carers the practical arrangements that will be needed after the death of their child, and provide this information in writing. This should cover matters such as:

- The care of the body
- Relevant legal considerations, including
    - The involvement of the child death overview panel
    - The involvement of the coroner
    - Registration of the death
- Funeral arrangements
- Post-mortem examination (if this is to be performed)

When a child or young person is approaching the end of life, discuss the bereavement support available with their parents or carers and provide them with written information.

When a child or young person is approaching the end of life, talk to their parents or carers about available psychological bereavement support groups.

Offer bereavement support from a professional with appropriate expertise to the parents or carers both before and after the death of a child or young person.

When planning bereavement support for parents or carers:

- Talk to them about the support that is available and explore with them what they would find helpful and acceptable
- Think about what support different professionals could provide, for example:
    - Their GP
    - Healthcare professionals who know the child or young person and are involved in their care
- Think about the role of individual professionals in providing specific aspects of support
- Inform the multidisciplinary team about the support plan.

When making a bereavement support plan with parents or carers, discuss possible options with them such as:

- Opportunities to talk to the professionals caring for the child or young person, to:
    - Discuss memories and events
    - Answer any concerns or questions they may have
- Home visits from the healthcare professionals caring for the child or young person
- Bereavement support groups

Ensure that arrangements are in place for professionals to talk about their thoughts and feelings with colleagues when a child or young person they are caring for is approaching the end of life or has died.

Following the death of a child or young person, a member of the multidisciplinary team should arrange in a timely manner for all relevant organisations and people to be informed.

Update relevant documents and databases after the death of a child or young person (to avoid, for example, clinical appointments being offered by mistake).

Service Delivery

Multidisciplinary Team

Children and young people with life-limiting conditions should be cared for by a defined multidisciplinary team.

As the child or young person's circumstances change (for example, if they change from having care primarily to manage their condition to having end of life care), the membership of the multidisciplinary team should be adjusted accordingly.

Depending on the needs of the child or young person, the multidisciplinary team may include:

- Healthcare professionals from primary, secondary or tertiary services, including specialists in the child's underlying life-limiting condition, hospice professionals and members of the specialist palliative care team (see recommendation below)
- Social care practitioners
- Education professionals
- Chaplains
- Allied health professionals (for example, physiotherapists, occupational therapists, and psychological therapists)

The specialist paediatric palliative care team should include at a minimum:

- A paediatric palliative care consultant
- A nurse with expertise in paediatric palliative care
- A pharmacist with expertise in specialist paediatric palliative care
- Experts in child and family support who have experience in end of life care (for example, in providing social, practical, emotional, psychological and spiritual support)

Explain to children and young people and their parents or carers:

- Who the multidisciplinary team members are and how they are involved in their care
- How the multidisciplinary team membership will change if the care that is needed or the care setting changes

Think about involving children and young people and their parents or carers in multidisciplinary team meetings (when appropriate).

Think about having a named individual from the multidisciplinary team to act as a first point of contact for the child or young person and their parents or carers.

Rapid Transfer Arrangements

In collaboration with local hospitals, hospices, and community, primary care and ambulance services, ensure there is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place (for example, from the intensive care unit to their home or to a children's hospice). See recommendations under "Preferred Place of Care and Pace of Death" above for the planning and practical arrangements of this transfer.

Care at Home

For children and young people with life-limiting conditions who are approaching the end of life and are being cared for at home, services should provide (when needed):

- Advice from a consultant in paediatric palliative care (for example, by telephone) at any time (day and night)
- Paediatric nursing care at any time (day and night)
- Home visits by a healthcare professional from the specialist paediatric palliative care team, for example, for symptom management
- Practical support and equipment for interventions including oxygen, enteral nutrition, and subcutaneous and intravenous therapies
- Anticipatory prescribing for children and young people who are likely to develop symptoms

Services should have agreed strategies and processes to support children and young people who are approaching the end of life and are being cared for at home. These services should be based on managed clinical networks, and should collaborate on care planning and service delivery.

Services for children and young people who are approaching the end of life and are being cared for at home should be able to support parenteral drug administration (for example, continuous subcutaneous opioid or anticonvulsant infusions).

Footnotes

[1]At the time of publication (2016) paracetamol did not have a UK marketing authorisation for use in children under 2 months of age by mouth, pre-term infants by IV infusion, children under 3 months rectally, children under 16 years as a concentrated liquid (500 mg/5 ml) for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[2]At the time of publication (2016) ibuprofen did not have a UK marketing authorisation for use in children under 3 months of age or weight less than 5 kg for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[3]At the time of publication (2016) oramorph liquid did not have a UK marketing authorisation for use in children under 1 year for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[4]At the time of publication (2016) sevredol tablets did not have a UK marketing authorisation for use in children under 6 years for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[5]At the time of publication (2016) gabapentin did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[6]At the time of publication (2016) amitriptyline did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[7]At the time of publication (2016) ketamine did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[8]At the time of publication (2016) methadone did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[9]At the time of publication (2016) midazolam injection did not have a UK marketing authorisation for use in children and buccolam did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[10]At the time of publication (2016) diazepam rectal tubes did not have a UK marketing authorisation for use in children under 1 year of age for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[11]At the time of publication (2016) lorazepam did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[12]At the time of publication (2016) haloperidol did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[13]At the time of publication (2016) levomepromazine did not have a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

Definitions

Strength of Recommendations

Some recommendations can be made with more certainty than others, depending on the quality of the underpinning evidence. The Committee makes a recommendation based on the trade-off between the benefits and harms of a system, process or an intervention, taking into account the quality of the underpinning evidence. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The Committee usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally the Committee uses 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The Committee uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of people, a system, process or an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer…') are used when the

Committee is confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The Committee uses 'consider' when confident that a system, process or an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Life-limiting conditions (i.e., any condition which either generally or in a particular individual is thought likely to result in early death)

Guideline Category

Counseling

Management

Clinical Specialty

Family Practice

Nursing

Pediatrics

Psychology

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Health Care Providers

Hospitals

Nurses

Other

Patients

Pharmacists

Psychologists/Non-physician Behavioral Health Clinicians

Social Workers

Guideline Objective(s)

- To provide guidance for planning and management of infants, children and young people (aged 0–17 years) with a life-limiting condition and their family members or carers
- To involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives

Target Population

Infants, children and young people aged up to 18 years who have a life-limiting condition and their family members or carers (as appropriate)

Note: The guideline does not cover adults aged 18 years and older and children and young people without a life-limiting condition who die unexpectedly (for example, accidental death).

Interventions and Practices Considered

1. Involving children and young people with life-limiting conditions and their parents or carers in decision-making and care planning
2. Appropriate communication based on their age and level of understanding and taking into account personal and family situation; religious, spiritual and cultural beliefs and values; and any special needs, such as communication aids or the need for interpreters
3. Providing information in an appropriate and sensitive manner
4. Advance care planning
5. Talking to the child or young person and their parents or carers about organ or tissue donation, and exploring their views and feelings
6. Providing emotional and psychological support and interventions
7. Providing social and practical support
8. Providing religious, spiritual, and cultural support
9. Discussing preferred place of care and place of death
10. Assessing and managing pain (pharmacological interventions)
11. Managing agitation
    - Nonpharmacological interventions such as reassurance
    - Pharmacological interventions including benzodiazepines or neuroleptics
12. Managing seizures
    - Treating or removing any potential causes, triggers or contributing factors
    - Use of anticonvulsants
13. Managing respiratory distress
14. Managing hydration
15. Managing nutrition
16. Recognising that a child or young person is likely to die within hours or days
17. Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person
18. Service delivery
    - Use of a multidisciplinary team
    - Rapid transfer agreements
    - Care at home

Major Outcomes Considered

- Quality of life of the child or young person and their family members or carers
- Satisfaction of the child or young person with their care
- Satisfaction with care of the family members, carers to the infant, child or young person
- Whether children and young people are able to die in a place they or their family members or carers choose
- Psychological well-being, (e.g., resilience, depression or anxiety) in the child or young person and their family members or carers
- Control of symptoms/preventing and managing pain and other distressing symptoms, for example, restlessness or agitation
- Adverse events, particularly opioid related

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

Clinical Evidence

Developing the Review Questions and Outcomes

Review Questions

Review questions were developed according to the type of question:

- Intervention reviews – in a PICO framework (patient, intervention, comparison and outcome)
- Reviews of diagnostic test accuracy – using population, index tests, reference standard and target condition
- Qualitative reviews – using population, area of interest and themes of interest
- Prognostic reviews – using population, presence or absence of a risk factor, and outcome

These frameworks guided the literature searching process, critical appraisal and synthesis of evidence and facilitated the development of recommendations by the Guideline Committee. The review questions were drafted by the National Guideline Alliance (NGA) technical team, then refined and validated by the Committee. The questions were based on the key clinical areas identified in the scope (see Appendix A).

A total of 20 review questions were identified (see Table 1 in the full version of the guideline).

Searching for Evidence

Clinical Literature Search

During the scoping stage, a search was conducted for guidelines and reports available on the Web sites of organisations which were relevant to the topic, and all references suggested by stakeholders during the scope consultation were considered for inclusion.

Systematic literature searches were undertaken to identify all published clinical evidence relevant to the review questions.

Databases were searched using relevant medical subject headings and free-text terms. Due to the large number of life-limiting conditions, it was considered appropriate to search primarily using terms related to end of life care. Where possible, searches were restricted to retrieve only English-language articles. Where appropriate, study type filters were applied. All searches were conducted in MEDLINE, EMBASE and The Cochrane Library. Where appropriate, certain searches were also conducted in PsycINFO, CINAHL or AMED. All searches were updated on 10 April 2016. Studies added to the databases after this date (even if they were published prior to this date) were not included unless specifically stated in the text.

Search strategies were quality-assured by cross-checking reference lists of key studies, analysing search strategies from other systematic reviews, and asking the Committee members to identify key studies. All search strategies were also quality-assured by a second information scientist working at the NGA, who had not created the strategies. Details of the searches, including study filters that were applied and databases that were used, can be found in Appendix E.

Grey and unpublished literature were not included in the searches, and searches for electronic, ahead-of-print publications were not routinely undertaken unless a particular study was identified by the Guideline Committee. Studies published in languages other than English were not

reviewed.

Health Economic Literature Search

A systematic literature search was undertaken to identify health economic evidence relevant to any review question. The evidence was identified by conducting a broad search relating to end-of-life care in the National Health Service Economic Evaluation Database (NHS EED) and the Health Technology Assessment (HTA) database with no date restrictions. Additionally, the same broad search was run on Medline, the Cochrane Central Register of Controlled Trials (CCTR) and EMBASE, with an economic filter applied. Where possible, searches were restricted to articles published in English, and studies published in languages other than English were not reviewed. The titles and abstracts of records retrieved by the broad search were sifted for relevance, and full-text copies of potentially relevant publications were obtained. These were assessed using the inclusion criteria specified in the protocol for each review question. The search strategies for the health economic literature search are included in Appendix F. All searches were updated on 10 April 2016. Any studies added to the databases after this date (even those published prior to this date) were not included unless specifically stated in the text.

Reviewing the Evidence

The evidence was reviewed following the steps shown schematically in Figure 2 in the full version of the guideline:

- Potentially relevant studies were identified for each review question from the relevant search results by reviewing titles and abstracts. Full papers were then obtained.
- Full papers were reviewed against pre-specified inclusion and exclusion criteria to identify studies that addressed the review question in the appropriate population, as outlined in the review protocols (review protocols are included in Appendix D).

Inclusion and Exclusion Criteria

The Committee was consulted about any uncertainty regarding inclusion or exclusion. The inclusion and exclusion of studies was based on the review protocols, which can be found in Appendix D. Excluded studies by review question (with the reasons for their exclusion) are listed in Appendix H.

In addition to the review protocols, there were particular inclusion and exclusion criteria which have been highlighted in Section 3.3.1 in the full version of the guideline.

Types of Studies

For most intervention reviews in this guideline, parallel randomised controlled trials (RCTs) were prioritised because they are considered the most robust type of study design that could produce an unbiased estimate of the intervention effects. The Committee expected there to be limited evidence of this type (due the study population being children or young people with life-limiting conditions), therefore non-randomised studies were also considered. This included consideration of uncontrolled studies (also called before-and-after studies without a control group). An uncontrolled before and after study is an observational study where either the same group of individuals are compared before and after a new intervention has been implemented, or where there is a group of participants before and then a different group of participants after the new treatment is implemented. The term uncontrolled is used as there is not a control group that has not received the intervention. Due to the lack of control group these studies have very low internal validity and are subjected to a very high-risk of bias. Despite this, the inclusion of such studies was considered in the absence of less biased evidence because this study design can be used when the selection of a control group is not practical or not ethical. This was noted when discussing the evidence and when drafting the recommendations.

For diagnostic reviews, cross-sectional and retrospective studies were considered for inclusion. For prognostic reviews, prospective and retrospective cohort studies were included. Case–control studies were not considered for inclusion.

In the qualitative reviews, studies using focus groups, or structured or semi-structured interviews were considered for inclusion. Survey data or other types of questionnaires were only included if they provided analysis from open-ended questions, but not if they reported descriptive quantitative data only.

Where data from observational studies were included, the Committee decided that the results for each outcome should be presented separately for each study and meta-analysis was not conducted.

Evidence of Cost-effectiveness

Literature Review

The health economist:

- Identified potentially relevant studies for each review question from the economic search results by reviewing titles and abstracts. Full papers were then obtained.
- Reviewed full papers against pre-specified inclusion and exclusion criteria to identify relevant studies (see below for details)

Studies initially considered eligible but which were then excluded can be found in Appendix H with explanations of the reasons for exclusion.

Inclusion and Exclusion Criteria

Full economic evaluations (studies comparing costs and health consequences of alternative courses of action [cost–utility, cost-effectiveness, cost–benefit and cost–consequences analyses]) and comparative costing studies that addressed a guideline review question in the relevant population were considered potentially includable as economic evidence.

Given the sparsity of full economic evaluations in the search, rigid exclusion criteria were not applied and articles were considered for inclusion if there was a significant resource content in a context relevant to a review question in the guideline.

Number of Source Documents

See Appendix F: Summary of identified studies in the full guideline appendices (see the "Availability of Companion Documents" field) for flow diagrams and detailed information on results of literature searches and the number of included and excluded studies for each review question. See Appendix K: Health economics for a flow diagram of health economic article selection for review. Only one economic publication was included in the review.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Overall Quality of Outcome Evidence in Grading of Recommendations Assessment, Development and Evaluation (GRADE)

Level	Description
High	Further research is very unlikely to change confidence in the estimate of effect.
Moderate	Further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate.
Low	Further research is very likely to have an important impact on confidence in the estimate of effect and is likely to change the estimate.
Very Low	Any estimate of effect is very uncertain.

Methods Used to Analyze the Evidence

Meta-Analysis

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

Reviewing and Synthesising the Evidence

After reviewing full papers against pre-specified inclusion and exclusion criteria, the evidence was reviewed as follows:

- Relevant studies were critically appraised using the appropriate checklist as specified in the National Institute for Health and Care Excellence (NICE) guidelines manual (NICE 2014) (see the "Availability of Companion Documents" field).
- Key information was extracted on the study's methods, according to the factors specified in the protocols and results. These were presented in summary tables (in each review chapter) and evidence tables (see Appendix G).
- Summaries of evidence were generated by outcome (included in the relevant review chapters) and were presented in Committee meetings (details of how the evidence was appraised are described below):
    - Randomised studies: meta-analysis was carried out where appropriate and results were reported in Grading of Recommendations Assessment, Development and Evaluation (GRADE) profiles (for intervention reviews).
    - Observational studies: data were presented as a range of values in GRADE profiles.
    - Prognostic studies: data were presented as a range of values, usually in terms of the relative effect as reported by the authors.
    - Diagnostic studies: data were presented as measures of diagnostic test accuracy (sensitivity, specificity, positive and negative predictive value).
    - Qualitative studies: each study was summarised by theme and meta-synthesis was carried out where appropriate to identify an overarching framework of themes and subthemes.

For quality assurance of study identification, either whole study selections or a sample of the study selection results were double checked by a second reviewer as follows:

- Service delivery (whole search for both rapid transfer and 24/7 service delivery)
- Psychological interventions (for children and for adults 10% of the search)
- Pain and agitation symptom management (all 10%)

A sample of all evidence tables was also quality assured and all write-ups of reviews were checked by a second reviewer. Any discrepancies were resolved by discussion between the 2 reviewers.

Methods of Combining Clinical Studies

Data Synthesis for Intervention Reviews

It was planned to conduct meta-analyses where possible to combine the results of studies for each review question using Cochrane Review Manager (RevMan5) software.

Fixed-effects (Mantel–Haenszel) techniques were used to calculate risk ratios (relative risk) for binary outcomes, such as rate of adverse events or rate of people with symptom improvements.

For continuous outcomes, measures of central tendency (mean) and variation (standard deviation) would be required for meta-analysis. Data for continuous outcomes (such as number of episodes of vomiting) were planned to be analysed using an inverse variance method for pooling weighted mean differences; where the studies had different scales, standardised mean differences were used. A generic inverse variance option in RevMan5 is used if any studies reported solely the summary statistics and 95% confidence interval (95% CI) or standard error (SE); this included any hazard ratios reported. However, in cases where standard deviations were not reported per intervention group, the standard error for the mean difference is calculated from other reported statistics (p values or 95% CIs): meta-analysis was then undertaken for the mean difference and SE using the generic inverse variance method in RevMan5. When the only evidence was based on studies that summarise results by presenting medians (and interquartile ranges) or only p values were given, this information was assessed in terms of the study's sample size and was included in the GRADE tables without calculating the relative or absolute effects. Consequently, aspects of quality assessment, such as imprecision of effect, could not be assessed for evidence of this type. However, the limited reporting of this outcome was classified as a risk of bias in study limitations.

Stratified analyses were predefined for some review questions at the protocol stage when the Committee identified that these strata are different in terms of biological and clinical characteristics and the interventions were expected to have a different effect.

Statistical heterogeneity was assessed by visually examining the forest plots, and by considering the chi-squared test for significance at $p<0.1$ or an I-squared inconsistency statistic (with an I-squared value of more than 50% indicating considerable heterogeneity). Where considerable heterogeneity was present, redefined subgroup analyses were carried out. For instance, in the pharmacological management of distressing symptoms, causes leading to the symptom would be a subgroup. The Committee also considered that, for instance, route of administration, delivery system and drug class could be possible reasons for heterogeneity in results. In case of unexplained heterogeneity, sensitivity analysis was planned to be carried out based on the quality of studies, eliminating studies at overall high risk of bias (randomisation, allocation concealment and blinding, missing outcome data).

Assessments of potential differences in effect between subgroups were based on the chi-squared tests for heterogeneity statistics between subgroups. If no sensitivity analysis was found to completely resolve statistical heterogeneity, then a random-effects (DerSimonian and Laird) model was employed to provide a more conservative estimate of the effect.

Refer to the full version of the guideline for details on methodology concerning data synthesis for prognostic factor reviews, diagnostic test accuracy reviews, and quality reviews.

Appraising the Quality of Evidence Using GRADE

Elements of GRADE

For intervention reviews, the evidence for outcomes from the included RCTs and observational studies were evaluated and presented using GRADE, which was developed by the international GRADE working group . Modified GRADE assessments were also carried out for outcomes per risk factor in prognostic reviews, accuracy measures in diagnostic reviews and themes in qualitative reviews.

The software developed by the GRADE working group (GRADEpro) was used to assess the quality of each outcome, taking into account individual study quality factors and the meta-analysis results. This software is used mainly for intervention reviews, but can also be used for prognostic reviews. It is not presently designed to assess evidence from diagnostic and qualitative reviews. Therefore the modified GRADE approach for diagnostic and qualitative evidence was carried out without the software but using similar tables and concepts which are described in the full version of the guideline. Results were presented in GRADE profiles 'GRADE tables'), which consist of 2 sections: the 'Clinical evidence profile' table includes details of the quality assessment, while the 'Clinical evidence summary of findings' table includes pooled outcome data and, where appropriate, an absolute measure of intervention effect and the summary of the quality of evidence for that outcome. In this table, the columns for intervention and control indicate summary measures and measures of dispersion (such as mean and standard deviation or median and range) for continuous outcomes, and frequency of events (n/N: the sum across studies of the number of patients with events divided by the sum of the number of completers, with 95% CIs) for binary outcomes. Reporting or publication bias was only taken into consideration in the quality assessment and included in the 'Clinical evidence profile' table if it was apparent.

The evidence for each outcome was examined separately for the quality elements listed and defined in Table 2 for intervention, Table 3 for prognostic, Table 4 for diagnostic, and Table 5 for qualitative reviews (see the full version of the guideline).

Grading the Quality of Clinical Evidence

After data were synthesised, the overall quality of evidence was assessed for each outcome (in intervention or prognostic reviews) by diagnostic sign and symptom, or qualitative theme. The following procedure was adopted when using GRADE:

- An initial quality rating was assigned, based on the study design. RCTs start as 'High' in intervention reviews, observational studies as 'Low', and uncontrolled case series as 'Low' or 'Very low'. In diagnostic, prognostic and qualitative reviews, evidence from nonrandomised studies start as High.
- The rating was then downgraded for the specified criteria: risk of bias (study limitations), inconsistency, indirectness, imprecision and publication bias. These criteria are detailed in Section 3.4.2 in the full version of the guideline. In intervention reviews, evidence from observational studies (which had not previously been downgraded) was upgraded if there was: a large magnitude of effect, and/or a dose–response gradient, and/or if all plausible confounding would reduce a demonstrated effect or suggest a spurious effect when results showed no effect. Each quality element considered to have 'serious' or 'very serious' risk of bias was rated down by 1 or 2 points respectively.
- The downgraded or upgraded marks were then summed and the overall quality rating was revised. For example, all RCTs started as High and the overall quality became Moderate, Low or Very low if 1, 2 or 3 points were deducted respectively.
- The reasons or criteria used for downgrading were specified in the footnotes.
- For qualitative reviews, a quality assessment of 'Unclear' was added to the list of possible GRADE-CERQual levels. Together with the Committee, it was decided that in qualitative reviews 1 'Unclear' rating did not mean an automatic downgrade of the evidence for this theme. However, 2 'Unclear' ratings were downgraded by 1 and 3 'Unclear' ratings downgraded by 2. Footnotes were not used for the CERQual tables. The details of the criteria used for each of the main quality elements are discussed further in Sections 3.3.4.2.1 to 3.3.4.2.5 of the full version of the guideline.

Assessing Clinical Significance (of Intervention Effects)

The Committee assessed the evidence by outcome in order to determine if there was, or potentially was, a clinically important benefit, a clinically important harm or no clinically important difference between interventions. To facilitate this, where possible, binary outcomes were converted into absolute risk differences (ARDs) using GRADEpro software: the median control group risk across studies was used to calculate the ARD and its 95% CI from the pooled risk ratio. For continuous outcomes, the mean difference between the intervention and control arm of the trail was

calculated. This was then assessed in relation to the default MID (0.5 times the median control group standard deviation).

The assessment of clinical benefit or harm, or no benefit or harm, was not based on the default MID of the relative risk, which was only used as a starting point, but on the point estimate of the absolute effect, taking into consideration the precision around this estimate.

The assessment was carried out by the Committee for each critical outcome, and an evidence summary table (used in the Committee meetings, but not presented in the guideline) was produced to compile the Committee's assessments of clinical importance per outcome, alongside the evidence quality and the uncertainty in the effect estimate (imprecision). In instances where the Committee decision differed from the default assessment, decisions were captured in the 'Linking evidence to recommendations' sections.

Refer to the full version of the guideline for details on methodology concerning assessing clinical significance of prognostic, diagnostic, or qualitative findings.

Evidence Statements

Evidence statements are summary statements that are presented after the GRADE profiles, summarising the key features of the clinical evidence presented. The wording of the evidence statements reflects the certainty or uncertainty in the estimate of effect. The evidence statements are presented by outcome or theme, and encompass the following key features of the evidence:

- The quality of the evidence (GRADE rating)
- The number of studies and the number of participants for a particular outcome
- A brief description of the participants
- An indication of the direction of effect (for example, if a treatment is beneficial or harmful compared with another, or whether there is no difference between the tested treatments)

Evidence of Cost-effectiveness

The Committee is required to make decisions based on the best available evidence of both clinical and cost-effectiveness. Guideline recommendations should be based on the expected costs of the different options in relation to their expected health benefits (that is, their 'cost-effectiveness') rather than the total implementation cost. Thus, if the evidence suggests that a strategy provides significant health benefits at an acceptable cost per patient treated, it should be recommended, even if it would be expensive to implement across the whole population.

Evidence on cost-effectiveness related to the key clinical issues being addressed in the guideline was sought, and a systematic review of the published economic literature was undertaken.

Literature Review

The health economist critically appraised relevant studies using the economic evaluations checklist as specified in the NICE guidelines manual.

Undertaking New Health Economic Analysis

As well as reviewing the published economic literature for guideline review questions, new economic analysis was undertaken by the health economist in selected areas. Priority areas for new health economic analysis were agreed by the Committee after formation of the review questions and consideration of the available health economic evidence. Owing to a lack of clinical or effectiveness evidence, these new analyses focused on costing aspects of service delivery.

Cost-effectiveness Criteria

It was recognised in the scope that the use of quality-adjusted life years (QALYs) was difficult in the context of end of life care for children and young people. The problems include the difficulties of eliciting health state utilities in this population, the often limited duration of life (which means that any QALY gains will typically be very small) and ethical issues around using conventional NICE cost effectiveness decision rules.

NICE's report Social value judgements: principles for the development of NICE guidance sets out the principles that Guidelines Committees should consider when judging whether an intervention offers good value for money, but also that that cost-effectiveness is not the sole criterion for making decisions and for the aforementioned reasons this is especially the case for this guideline.

In general, an intervention was considered to be cost effective if either of the following criteria applied (given that the estimate was considered plausible):

- The intervention dominated other relevant strategies (that is, it was both less costly in terms of resource use and more clinically effective compared with all the other relevant alternative strategies); or

- The intervention provided clinically significant benefits at an acceptable additional cost when compared with the next best strategy

In the Absence of Economic Evidence

When no relevant published studies were found, the Committee made a qualitative judgement about cost-effectiveness by considering expected differences in resource use between options and relevant UK NHS unit costs, alongside the results of the clinical review of effectiveness evidence and using their expert opinions.

The costs reported in the guideline are those that were presented to the Committee and were correct at the time the recommendations in this guideline were drafted. They may have changed subsequently before the time of publication, but the Committee has no reason to believe they have changed substantially.

Methods Used to Formulate the Recommendations

Expert Consensus

Informal Consensus

Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): This guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance.

Involving Children and Young People with Life-limiting Conditions in This Guideline – Focus Group Research

Background

An integral part of the development process of this guideline was the involvement of people with direct experience of the condition and the services available to them. The Committee included 2 mothers of children who had died because of a life-limiting condition. They contributed as full guideline members, developing review questions, highlighting sensitive issues and terminology, and bringing the experience of parents to the attention of the rest of the Committee. However, as part of the scoping process it was identified that there was limited evidence directly from the children and young people's perspective. For this topic it was considered crucial that the experiences, perspectives and opinions of children and young people would be incorporated in the guideline. The topics which were prioritised to benefit particularly from the input of children and young people with life-limiting conditions were:

- Information: the information given to them with regard to their condition and its management.
- Communication: how that information should be made available, for example 1-to-1 discussion.
- Place of care: their views on where they would ideally like to receive care – and the factors that influence their thoughts on this.
- Care planning: how they would like to be involved in planning their own care.
- Psychological and other support needs: what kind of emotional and other support they consider to be important and helpful to them in living with their condition.

Additionally, the Committee wanted to know what children and young people with life-limiting conditions thought about their current care in terms of:

- What areas of care were currently being 'done well' and where was the care less satisfactory?
- If they could change one thing about their care, what would it be?

Focus groups with children and young people with life-limiting conditions were conducted for this guideline. The findings of this research was used as direct evidence in Chapter 4 (Providing Information) and Chapter 5 (Communication), and in Sections 6.1 and 8.18.1 (see the full version of the guideline). The details of this primary research project can be found in Appendix L.

This work was carried out by Together for Short Lives, an organisation representing the needs of children and young people with life-limiting conditions.

Methods with Regard to the Focus Group

The details of the focus group methodology are described in Appendix L.

The organisation conducted 3 focus groups: 1 in the North of England (Yorkshire), 1 in Bristol (where Together for Short Lives is based) and 1 in London, in order to ensure broad representation of participants across the UK. A total of 14 young people took part (7 male, 7 female), ranging in age from 12 to 18 years. Conditions included spinal muscular atrophy, cancer, cystic fibrosis, and other rare degenerative and life-threatening conditions. Key findings were shared with all participants and feedback received from 7 young people was used to help interpret the findings of the focus group.

Drawing on Children's and Young People's Views to Inform Recommendations

A member of the research team from Together for Short Lives presented the findings from the focus group at a Committee meeting and the full report was circulated. The themes that emerged were presented to the Committee and, together with any other identified evidence for the topics, were taken into consideration when the recommendations were drafted. This was the most applicable evidence for a number of the topics covered by the guideline, and therefore influenced the recommendations directly. The Committee therefore decided to highlight the contributions of the children and young people in a specific section in the 'Evidence to recommendations' sections of the full version of the guideline, which provide the rationale for the recommendations.

Developing Recommendations

Over the course of the guideline development process, the Guideline Committee was presented with:

- Evidence tables of the clinical and economic evidence reviewed from the literature (all evidence tables are in Appendix G)
- Summaries of clinical and economic evidence and quality assessment (as presented in Chapters 5 to 11 in the full version of the guideline)
- Forest plots, when applicable (Appendix I)
- A description of the methods and results of the cost-effectiveness analysis undertaken for the guideline (Appendix K)

Recommendations were drafted on the basis of the Committee's interpretation of the available evidence. For intervention studies, this would mean taking into account the balance of benefits, harms and costs between different courses of action. This was either done formally, in an economic model, or informally. Firstly, the net benefit over harm (clinical effectiveness) was considered in discussion with the Committee, focusing on the critical outcomes. When this was done informally, the Committee took into account the clinical benefits and harms when one intervention was compared with another. The assessment of net benefit was moderated by the importance placed on the outcomes (the Committee's values and preferences) and the confidence the Committee had in the evidence (evidence quality). Secondly, the Committee assessed whether the net benefit justified any differences in costs.

When clinical and economic evidence was of poor quality, conflicting or absent, the Committee drafted recommendations based on their expert opinions. The considerations for making consensus-based recommendations include the balance between potential harms and benefits, the economic costs or implications compared with the economic benefits, current practices, recommendations made in other relevant guidelines, patient preferences and equality issues. The Committee also considered whether the uncertainty was sufficient to justify delaying making a recommendation and awaiting further research.

The wording of recommendations was agreed by the Committee and focused on the following factors:

- The actions healthcare professionals need to take
- The information readers need to know
- The strength of the recommendation (for example the word 'offer' was used for strong recommendations and 'consider' for weak recommendations)
- The involvement of people with the condition (and their parents or carers if needed) in decisions about treatment and care
- Consistency with National Institute for Health and Care Excellence (NICE) standard advice on recommendations about drugs, waiting times and ineffective interventions.

In cases of qualitative evidence, the Committee considered the themes that had been identified from the meta-synthesis or from the focus group (for instance barriers and facilitators for effective care planning), and assessed whether they were generalisable to the National Health Service (NHS) context. This included an interpretation of how a concept originating from a named theme from the literature could apply to clinical practice. For example, in the 'Religious, spiritual and cultural support' review, the theme of 'ready to die and go to heaven' may highlight that clinicians should be aware of the impact of religious, spiritual and cultural beliefs on end of life care planning.

The main considerations of the Committee specific to each recommendation are outlined in the 'Recommendations and link to evidence' sections within each chapter of the full version of the guideline.

Rating Scheme for the Strength of the Recommendations

Strength of Recommendations

Some recommendations can be made with more certainty than others, depending on the quality of the underpinning evidence. The Committee makes a recommendation based on the trade-off between the benefits and harms of a system, process or an intervention, taking into account the quality of the underpinning evidence. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The Committee usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally the Committee uses 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The Committee uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of people, a system, process or an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer…') are used when the Committee is confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The Committee uses 'consider' when confident that a system, process or an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

Cost Analysis

See the "Economic evidence" sections of the full version of the guideline.

A single health economic paper was identified from the literature search for economic evidence as relevant to the review question on day-and-night community nursing support and day-and-night specialist advice. This paper estimated an additional cost of £336,000 per year (or £14,000 per child) to provide 1 week of day-and-night end of life care at home to 24 children in North Wales. This paper is reviewed in more detail in Appendix K on Health economics (see the "Availability of Companion Documents field).

A costing model was produced for this guideline to compare the costs of a day-and-night community nursing support and day-and-night specialist telephone advice for children and young people receiving home care and approaching the end of life. This model is briefly summarised in the full version of guideline but is described in full in Appendix K.

The systematic search undertaken for this guideline did not identify any relevant economic literature relating to rapid transfer to take children and young people with a life-limiting illness to their preferred place of care in their last days of life.

A costing model was produced for this guideline to compare the costs of providing a rapid transfer service with an alternative where no such service was provided. This model is briefly summarised in the full version of the guideline and is described in full in Appendix K.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Validation Process

This guidance was subject to a 6-week public consultation and feedback as part of the quality assurance and peer review of the document. All

comments received from registered stakeholders were responded to in turn and posted on the National Institute for Health and Care Excellence (NICE) Web site when the prepublication check of the full guideline occurred. See Chapter 10 of Developing NICE guidelines: the manual (2014) (see the "Availability of Companion Documents" field) for more information on the validation process for draft guidelines, and dealing with stakeholder comments.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

See "Types of Studies" in the "Description of Methods Used to Collect/Select the Evidence" field for information on the type of studies used to formulate the recommendations. Also see the "Evidence statements" for each review question in the full version of the guideline (see the "Availability of Companion Documents" field) for the key features of the studies supporting each question.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

- Provision of physical, emotional, social and spiritual elements of end of life care
- Improvement of the child's or young person's quality of life and support of their family

See the "Consideration of clinical benefits and harms" sections in the full version of the guideline (see the "Availability of Companion Documents" field) for details about potential benefits of specific interventions.

Potential Harms

- Adverse events of medications, particularly opioid related, such as constipation, nausea/vomiting, itching, urinary retention, fatigue, confusion, respiratory depression, and unwanted levels of sedation
- Adverse events associated with medically assisted hydration and nutrition, including vomiting, respiratory distress, and abdominal pain

See the "Consideration of clinical benefits and harms" sections in the full version of the guideline (see the "Availability of Companion Documents" field) for details about potential harms of specific interventions.

Qualifying Statements

Qualifying Statements

- The recommendations in this guideline represent the view of the National Institute for Health and Care Excellence (NICE), arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The application of the recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.
- Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.
- The National Guideline Alliance (NGA) disclaims any responsibility for damages arising out of the use or non-use of these guidelines and the

literature used in support of these guidelines.

Implementation of the Guideline

Description of Implementation Strategy

Implementation: Getting Started

The National Institute for Health and Care Excellence (NICE) has produced tools and resources to help put this guideline into practice (see also the "Availability of Companion Documents" field).

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. Raise awareness through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.
2. Identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.
3. Carry out a baseline assessment against the recommendations to find out whether there are gaps in current service provision.
4. Think about what data you need to measure improvement and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.
5. Develop an action plan, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.
6. For very big changes include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.
7. Implement the action plan with oversight from the lead and the project group. Big projects may also need project management support.
8. Review and monitor how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See the into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Implementation Tools

Mobile Device Resources

Patient Resources

Resources

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

National Guideline Alliance. End of life care for infants, children and young people with life-limiting conditions: planning and management. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Dec 7. 44 p. (NICE guideline; no. 61).

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2016 Dec 7

Guideline Developer(s)

National Guideline Alliance - National Government Agency [Non-U.S.]

Source(s) of Funding

The National Guideline Alliance was commissioned by the National Institute for Health and Care Excellence (NICE) to undertake the work on this guideline.

Guideline Committee

Guideline Committee

Composition of Group That Authored the Guideline

Guideline Committee Members: Peter Barry, Consultant Paediatric Intensivist, University Hospitals of Leicester; Karen Brombley, Nurse

Consultant for Children and Young People's Palliative Care, Helen & Douglas House Hospices, Honorary Nurse Consultant, Oxford University Hospital NHS Trust; Lucy Coombes, Caroline Menez Research Sister and Clinical Nurse Specialist, Children and Young People's Outreach and Symptom Care Team, Royal Marsden NHS Foundation Trust; Stacey Curzon (from November 2015), Youth Worker, Rainbows Hospice for Children and Young People; Bobbie Farsides, Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School; Jane Green, Patient and carer member; Satbir Jassal, General Practitioner, Bridge Street Medical Practice; Emily Harrop (*Deputy Chair from April 2016*), Consultant in Paediatric Palliative Care, Helen & Douglas House Hospices, Honorary Consultant, Oxford University Hospital NHS Trust; Paul Nash, Senior Chaplain, Birmingham Children's Hospital NHSFT and Co-convenor Paediatric Chaplaincy Network (Great Britain and Ireland); Fauzia Paize (from May 2015), Neonatologist, Liverpool Women's NHS Foundation Trust; Zoe Picton-Howell, Patient and carer member; David Vickers (*Chair*), Consultant Paediatrician, Cambridgeshire Community Services NHS Trust; Amy Volans, Lead Clinical Psychologist and Systemic Family Psychotherapist, Diana Children's Community Palliative Care Team, East London NHS Foundation Trust; Claire Wensley, Consultant Paediatrician, York Teaching Hospital NHS Foundation Trust; Sharon English (until March 2015), Consultant in Neonatal Medicine Leeds Centre for Newborn Care, Leeds Children's Hospital, Leeds Teaching Hospitals NHS Trust (LTHT); Elissa Coster (until September 2015), Children and Families Worker, The Brain Tumour Charity

Co-opted Members: David Hamilton, Bereavement Support Co-ordinator and Counsellor, Rainbows Hospice for Children and Young People; Afia Manaf, Pharmacist, Paediatric Critical Care, Royal Manchester Children's Hospital; Susan Lee, Specialist Nurse Organ Donation, NHS Blood and Transplant

Financial Disclosures/Conflicts of Interest

All Committee members' interests were recorded on declaration forms provided by National Institute for Health and Care Excellence (NICE). The form covered personal, non-personal, specific or non-specific and non-financial or financial declarations. Committee members' declarations of interests are listed in Appendix C (see the "Availability of Companion Documents" field).

No conflicts were identified that required a Committee member to be asked not to participate in the relevant discussions. Details are available from the Committee minutes available on the NICE Web site where the policy can also be accessed.

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Available from the National Institute for Health and Care Excellence (NICE) Web site. Also available for download in eBook and ePub formats from the NICE Web site.

Availability of Companion Documents

The following are available:

- End of life care for infants, children and young people with life-limiting conditions: planning and management. Full guideline. London (UK): National Institute for Health and Care Excellence; 2016 Dec. 460 p. (NICE guideline; no. 61). Available from the National Institute for Health and Care Excellence (NICE) Web site.
- End of life care for infants, children and young people with life-limiting conditions: planning and management. Appendices. London (UK): National Institute for Health and Care Excellence; 2016 Dec. (NICE guideline; no. 61). Available from the NICE Web site.
- End of life care for infants, children and young people with life-limiting conditions: planning and management. Baseline assessment tool. London (UK): National Institute for Health and Care Excellence; 2016 Dec. (NICE guideline; no. 61). Available from the NICE Web site.
- End of life care for infants, children and young people with life-limiting conditions: planning and management. Resource impact report. London (UK): National Institute for Health and Care Excellence; 2016 Dec. 16 p. (NICE guideline; no. 61). Available from the NICE

Web site .

- End of life care for infants, children and young people with life-limiting conditions: planning and management. Resource impact template. London (UK): National Institute for Health and Care Excellence; 2016 Dec. (NICE guideline; no. 61). Available from the NICE Web site .
- The guidelines manual 2012. London (UK): National Institute for Health and Care Excellence (NICE); 2012 Nov. Available from the NICE Web site .
- Developing NICE guidelines: the manual. London (UK): National Institute for Health and Care Excellence (NICE); 2014 Oct. Available from the NICE Web site .

Patient Resources

The following are available:

- End of life care for children and young people: information for carers. Information for the public. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Dec. 13 p. Available from the National Institute for Health and Care Excellence (NICE) Web site . Also available for download in eBook and ePub formats from the NICE Web site .
- End of life care for children and young people: information for young people. Information for the public. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Dec. 3 p. Available from the NICE Web site . Also available for download in eBook and ePub formats from the NICE Web site .

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC Status

This NGC summary was completed by ECRI Institute on March 1, 2017.

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